House Bill 1066 (AS PASSED HOUSE AND SENATE)

By: Representatives Manning of the 32nd, Ehrhart of the 36th, O'Neal of the 146th, Cooper of the 41st, Brown of the 69th, and others

A BILL TO BE ENTITLED

AN ACT

- 1 To amend Chapter 12 of Title 31 of the Official Code of Georgia Annotated, relating to
- 2 control of hazardous conditions, preventable diseases, and metabolic disorders, so as to
- 3 change certain provisions relating to a system for screening newborns for certain metabolic
- 4 and genetic disorders; to provide for the establishment of fees; to provide for religious
- 5 objection to screening; to change certain provisions relating to screening for phenylketonuria,
- 6 sickle cell anemia, and sickle cell trait; to provide for related matters; to provide for an
- 7 effective date; to repeal conflicting laws; and for other purposes.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF GEORGIA:

9 SECTION 1.

- 10 Chapter 12 of Title 31 of the Official Code of Georgia Annotated, relating to control of
- 11 hazardous conditions, preventable diseases, and metabolic disorders, is amended by striking
- 12 Code Section 31-12-6, relating to a system for prevention of mental retardation resulting
- 13 inherited metabolic disorders, and inserting in lieu thereof the following:
- 14 "31-12-6.

8

- 15 (a) The department shall promulgate rules and regulations creating a system for the
- prevention of mental retardation serious illness, severe physical or developmental
- 17 <u>disability, and death</u> caused by <u>genetic conditions, such as</u> phenylketonuria, galactosemia,
- 18 tyrosinemia, homocystinuria, maple syrup urine disease, hypothyroidism, congenital
- adrenal hyperplasia, and such other inherited metabolic and genetic disorders as may be
- 20 determined identified in the future to result in serious illness, severe physical or
- 21 <u>developmental disability, and death cause mental retardation</u> if undiagnosed and untreated.
- The system shall have five components: screening newborns for the disorders; retrieving
- potentially affected screenees back into the health care system; accomplishing specific
- diagnoses; initiating and continuing therapy; and assessing the program.

1 (b) The entire process for screening, retrieval, and diagnosis must occur within the first

- 2 three weeks of an infant's life time frames established by the department pursuant to rules
- 3 <u>and regulations</u>, and the system shall be structured to meet this critical need.
- 4 (c) The department shall be responsible for the screening of all newborns for the disorder
- 5 <u>disorders enumerated and in a manner determined by the department pursuant to rules and</u>
- 6 <u>regulations</u> and shall be responsible for assessment of the program.
- 7 (d) The department shall, to the extent state or federal funds are available for such
- 8 purposes, including but not limited to funds provided under Title V of the Social Security
- 9 Act, the Maternal and Child Health Services Block Grant, provide for retrieving potentially
- affected screenees back into the health care system; accomplishing specific diagnoses;
- initiating and continuing therapy; and assessing the program.
- 12 (e) Because the rudiments of such a system already exist, the <u>The</u> department shall utilize
- appropriate existing resources whenever possible and shall cause the coordination and
- 14 cooperation of agencies and organizations having resources necessary for the creation of
- an effective system.
- 16 (f) The department shall be authorized to establish and periodically adjust, by rule and
- 17 regulation, fees associated with the screening, retrieval, and diagnosis conducted pursuant
- 18 to this Code section to help defray or meet the costs incurred by the department. In no
- 19 event shall the fees exceed such costs, both direct and indirect, in providing such
- 20 screenings and related services, provided that no services shall be denied on the basis of
- 21 <u>inability to pay. All fees paid thereunder shall be paid into the general fund of the State of</u>
- 22 Georgia.
- 23 (g) The department shall allow any laboratory licensed in Georgia and authorized to
- 24 perform screening testing of newborn infants in any state using normal pediatric reference
- 25 ranges to conduct the analysis required pursuant to this Code section. The testing
- 26 performed by such laboratory must include testing for newborn diseases as required by law
- 27 or regulation and shall provide test results and reports consistent with law and with
- 28 policies, procedures, and regulations of the department.
- 29 (h) No later than January 1, 2007, the Georgia Department of Audits and Accounts shall
- 30 conduct an assessment evaluating the efficiency and effectiveness of the newborn
- 31 screenings conducted by the Georgia Public Health Laboratory pursuant to this Code
- 32 section. If it is determined that private laboratories can provide testing at a lower cost than
- 33 <u>the Georgia Public Health Laboratory, the department shall issue a request for proposals</u>
- 34 <u>to qualified vendors including any private laboratory licensed in Georgia as established in</u>
- 35 <u>subsection (g) of this Code section. The Georgia Public Health Laboratory shall be eligible</u>
- 36 to respond to such request for proposals.

1 (i) The requirements of this Code section with regard to screening, retrieval, and diagnosis

- 2 shall not apply to any infant whose parents object in writing thereto on the grounds that
- 3 <u>such tests and treatment conflict with their religious tenets and practices."</u>

4 SECTION 2.

- 5 Said chapter is further amended by striking Code Section 31-12-7, relating to rules and
- 6 regulations regarding tests for phenylketonuria, sickle cell anemia, and sickle cell trait, and
- 7 inserting in lieu thereof the following:
- 8 "31-12-7.
- 9 (a) In coordination and association with the system established by the department for the
- screening, retrieval, and diagnosis of certain metabolic and genetic disorders pursuant to
- 11 <u>Code Section 31-12-6, the The department, or its successor agency or department, shall</u>
- 12 adopt and promulgate appropriate rules and regulations governing tests for
- phenylketonuria, sickle cell anemia, and sickle cell trait, and other metabolic and genetic
- 14 <u>disorders as enumerated by the department pursuant to rules and regulations</u> so that as
- 15 nearly as possible all newborn infants who are susceptible or likely to have
- phenylketonuria, sickle cell anemia, or sickle cell trait, or other metabolic and genetic
- 17 <u>disorders</u> shall receive a test for phenylketonuria, sickle cell anemia, or sickle cell trait, <u>or</u>
- 18 <u>other metabolic and genetic disorders</u> or all of such conditions as soon after birth as
- successful testing and treatment therefor may be initiated; provided, however, that this
- 20 Code section shall not apply to any infant whose parents object thereto on the grounds that
- such tests and treatment conflict with their religious tenets and practices.
- 22 (b) If any such child is found to have phenylketonuria, sickle cell anemia, or sickle cell
- trait, it shall be the duty of the examining physician or the department to inform the parents
- of such child that the child is so afflicted and, if such child has sickle cell anemia or sickle
- cell trait, that counseling regarding the nature of the disease, its effects, and its treatment
- is available without cost from the department and the county board of health or county
- department of health.
- 28 (c) It shall be the duty of the department and each county board of health and county
- department of health, or their successor agencies or departments, to furnish counseling and
- advice to any persons requesting such counseling regarding sickle cell anemia or sickle cell
- trait, its characteristics, symptoms, traits, effects, and treatment. Such counseling shall be
- furnished without cost to the person requesting it.
- 33 (d) The department shall be authorized to establish and periodically adjust, by rule and
- 34 regulation, fees associated with the screening, retrieval, and diagnosis conducted pursuant
- 35 to this Code section to help defray or meet the costs incurred by the department; provided,

1 however, that in no event shall the total fees associated with such screening, retrieval, and

- 2 diagnosis exceed \$40.00 for the calendar year beginning January 1, 2007. In no event shall
- 3 the fees exceed such costs, both direct and indirect, in providing such screenings and
- 4 <u>related services, provided that no services shall be denied on the basis of inability to pay.</u>
- 5 All fees paid thereunder shall be paid into the general fund of the State of Georgia."
- 6 SECTION 3.
- 7 This Act shall become effective on January 1, 2007.
- 8 SECTION 4.
- 9 All laws and parts of laws in conflict with this Act are repealed.